FAMILY ENVIRONMENT, SOCIAL SUPPORT, AND PSYCHOLOGICAL DISTRESS OF WOMEN SEEKING BRCA1 AND BRCA2 GENETIC MUTATION TESTING

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Shared characteristics and predictors of psychological distress are beginning to be identified in research on women seeking genetic testing for BRCA1 and BRCA2 gene mutations. This study further explored patterns of psychological distress for 51 community women waiting to receive such genetic test results. There was no significant relationship between psychological distress and family cancer history, personal cancer history, social support networks, and family environment. Women in this sample tended to rely more on females and relatives for support than males and friends. Social support satisfaction was not related to gender or number of relatives providing support. Thirty-four of the 36 women classified on the family environment type were from Personal Growth-Oriented families. Comparisons with normal and distressed family means revealed increased cohesion and expressiveness with decreased conflict, indicative of supportive family environments. Limitations and implications are discussed.

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CHAPTER I

INTRODUCTION

In 1998, more than 180,000 women in the United States were diagnosed with breast cancer (American Cancer Society, 1998). Breast cancer is more common than any other type of cancer in women. Although much less common, ovarian cancer is also an important woman's health issue with more than 26,000 cases diagnosed in the United States in 1996 (Audrain, Schwartz, Lerman, Hughes, Peshkin, & Biesecker, 1997). Most breast and ovarian cancers are sporadic in nature, occurring without known genetic or other highly elevated risk factors. With sporadic cancer, the risk of developing ovarian cancer does not increase with incidence of breast cancer. This risk, however, does increase if a breast cancer is determined genetic in origin. There are, however, several risk factors that increase a woman's likelihood of developing breast and/or ovarian cancer. One risk factor is age. The risk of breast cancer increases over the lifetime. The annual incidence of breast cancer in women in the United States ages 80 to 85 years old is fifteen times higher than among women 30 to 35 years old (Vogel, 1996). A second risk factor, age at menarche and age at menopause, is also related to a woman's chance of developing breast cancer. Early menarche and late menopause lead to an increased risk of breast cancer of 30% to 50% (Kelsey, 1979; Vogel, 1996). A third major risk factor is a family history of cancer. The risk of breast and ovarian cancer increases with the number of first-degree relatives who have had the disease (Nayfield, Karp, Ford, Dorr, & Kramer, 1991). More than two first-degree relatives with breast and/or ovarian cancer significantly increases a women's risk for developing cancer (Vogel, 1996).

In addition, related to family history of cancer, there is also a direct genetic link to breast and ovarian cancer. An estimated 5% to 10% of breast cancer cases are thought to be due to hereditary genetic mutations (Blum & Tomlinson, 1994; Burke et al., 1997). Mutations in two genes, BRCA1 and BRCA2, are estimated to account for most of these hereditary breast cancer cases (Miki et al., 1994; Wooster et al., 1994). BRCA1 and BRCA2 are tumor suppressor genes, whose proteins act like cellular mechanics to repair damaged DNA and suppress tumor formation. If there is a mutation on either of these genes, this repair function is lost and the regulation of cell division is impaired (National Institutes of Health, 1996). Both mother and father can pass a mutated copy of the BRCA1 and BRCA2 genes to their children.

The BRCA1 gene is located on chromosome 17q21 (Hall et al., 1992). Cumulative risk of breast cancer in women with BRCA1 mutations is estimated to be 3.2% by age 30, 19.1% by age 40, 50.8% by age 50, 54.2% by age 60, and 85% by age 70 (Easton, Ford, Bishop, & Breast Cancer linkage Consortium, 1995). This is in comparison to a risk of only 7% in the general population by the age of 70 years. The risk for ovarian cancer seems to be variable, but is estimated at a cumulative risk of 26% by 70 years of age for most genetic mutation carriers (Burke et al., 1997). The BRCA1 genetic mutation appears to account for 45% of families with a significantly high incidence of breast cancer and 80% of families with an increased incidence of both early onset breast and ovarian cancer (Vogel, 1996). In an analysis of 214 families with first- and second-degree relatives with breast and/or ovarian cancer, Easton et al. (1993) showed that a BRCA1 mutation was responsible for almost all of the families with

multiple cases of both breast and ovarian cancers, and approximately half of the families with multiple cases of breast cancer alone.

The BRCA2 gene is located on chromosome 13q12-13 (Wooster et al., 1994). Women with BRCA2 mutations appear to have a breast cancer risk similar to that of women with BRCA1 mutations (Ford & Easton, 1995). Ovarian cancer risk is estimated at approximately 10% by age 70 years. There is also new research that is beginning to find an association between BRCA1 and BRCA2 and other cancers including prostate and colorectal cancer. One study reported a four-fold increased risk of developing colon cancer with a BRCA1 mutation (Ford et al., 1994).

More than 400 different mutations in BRCA1 and BRCA2 have been identified (The Breast Cancer Information Core, 1996). Each family tends to have its own mutation. Consequently, identifying germline mutations usually requires the complex task of sequencing the DNA for both genes in the genetic participant. Only a few mutations have been found to occur in multiple families. Three mutations are especially common in the Ashkenazi Jewish population. An estimated 1 in 40 Ashkenazi Jewish persons, regardless of family cancer history, are carriers of one of these three mutations (Roa et al., 1996).

As technology and medicine continue to advance in the identification of genetic mutations, commercial genetic testing is becoming more available for individuals who perceive themselves to be at high-risk. Research supports a desire for genetic testing, especially for those with a family history of cancer. Lerman et al. (1995) reported that 91% of women who had first-degree relatives with breast cancer indicated that they would seek genetic counseling if available. Similarly, 75% of first-degree relatives of

ovarian cancer patients indicated that they would definitely want to be tested, and 20% stated they probably would get tested (Lerman, Daly, Masny, & Balshem, 1994).

There are many benefits of genetic testing. It reduces uncertainty and may protect future health (Lerman & Croyle, 1994). Those who find they are not mutation carriers experience a sense of relief and an improvement in quality of life. Genetic testing allows for identification of individuals at greater risk for developing cancer. This information can then be used to increase surveillance behaviors and improve adherence to preventative screening behaviors such as mammography and breast self-examination. This can increase the probability that breast cancer will be detected at an earlier stage, improving prognosis. Genetic testing also potentially provides information about one's children's risks as well.

Genetic testing for BRCA1 and BRCA2 mutations is a relatively new field of study. Self-referred commercial testing has only been available for a few years. Hence, there has been little examination of the possible negative consequences of genetic testing (Kodish, Wiesner, Mehlman, & Murray, 1998). Also, there have been limited investigations into the shared characteristics of self-referred individuals.

Individuals who seek genetic testing often perceive themselves to be at high-risk for developing cancer. Many actually overestimate their risk (Bluman et al., 1999; Lerman et al., 1995). Women from families with a high incidence of breast and/or ovarian cancer frequently believe having a mutation is nearly a certainty. Lerman et al. (1995) reported that even after individual breast cancer risk counseling, almost two-thirds of these women greatly overestimated their risk three months after the session.

Psychological Distress

There is also evidence of varying levels of psychological distress in women who are at high familial risk for developing breast and/or ovarian cancer. Psychological distress can be examined as general distress (e.g., increased general anxiety and/or depression) or cancer specific distress (e.g., intrusive thoughts about cancer). Research has indicated that women with a family history of breast and/or ovarian cancer experience a range of adjustment difficulties and may be more emotionally vulnerable than those without this history (Lerman & Schwartz, 1993; Valdimarsdottir et al., 1995). Kash, Holland, Halper, and Miller (1992) reported that 27% of high-risk women who self-referred to a breast cancer screening program exhibited sufficient distress to warrant psychological counseling. A population based study of first-degree relatives of patients with breast cancer revealed that half of the women experienced traumatic stress symptoms related to their breast cancer risk. These symptoms included intrusive thoughts, sleep disturbances, and impairment in daily activities (Lerman et al., 1993). Thus, psychological distress is important to study in association with genetic testing.

Distress about cancer risk has been found to be a predictor of depression and impediment to both surveillance behaviors and the comprehension of medical information and genetic test results (Lerman et al., 1997). One study indicated that the presence of cancer related stress symptoms was highly predictive of subsequent depression in hereditary breast and ovarian cancer family members. In Stefanek, Wilcox, and Huelskamp's (1992) study of first-degree relatives of women with breast cancer, 40% to 60% of these high-risk women practiced breast self-examinations less than the

once per month recommended by the American Cancer Society. Variables contributing to a lack of adherence were anxiety about positive test results and a perceived vulnerability to breast cancer. Kash et al. (1992) reported that adherence to guidelines for clinical breast exams decreased as psychological distress increased. In a study with 503 high-risk women, only 27% performed regular breast self-examinations (Kash, 1995). These low rates of screening were attributed to higher levels of psychological distress in these women.

Some predictors of psychological distress have been identified. Kash (1995) found perceived barriers to screening behaviors, less social support, and less use of denial were predictors of increased psychological distress. Lesniak (2000) reported women under 50 years of age (pre-menopausal) tended to have more overall distress than women over age 50 (post-menopausal). It was also shown that those with higher levels of education tended to be more vulnerable to distress. Finally, women of Ashkenazi Jewish descent reported higher levels of psychological distress than other Caucasian women. This may be partially attributed to the BRCA1 and BRCA2 mutations that have been identified as being specific to Ashkenazi Jewish people. Knowledge of these mutations may lead to an increased perceived risk and increased worries about developing cancer.

Family History of Cancer

A family history of cancer is one potential stressor which may increase women's distress. Research has also shown that past life events, such as a family member dying from cancer, along with current stressors contribute to psychological distress (Butler, Koopman, Classes, & Spiegel, 1999). Worries regarding future cancer may combine with

past family based exposure to cancer-related events to increase women's distress (Erblich, Bovbjerb, & Valdimarsdottir, 2000). These women often feel powerless and experience heightened anxiety regarding developing breast cancer. Thus, a woman's sense of self-efficacy regarding the prevention of breast cancer is often lacking. In contrast, however, Lesniak (2000) reported that among women seeking genetic testing those with a greater number of first-degree relatives with any type of cancer had less psychological distress. In a study of 149 high-risk individuals from hereditary cancer families, Lerman et al. (1997) did not find that distress levels were positively related to the number of first-degree relatives with breast and ovarian cancer. The conflicting findings indicate that family history needs to be examined more extensively among different groups of women to determine which specific aspects of family relations and family cancer history are predictive of psychological distress.

Attachment theory suggests the age of a woman when her mother developed cancer may be an important component of distress. Attachment refers to a relational bond between two people (Bowlby, 1988). The course of development of attachment in children seems to move from overwhelming dependence to relative autonomy. Small children require a parent's presence in a strange environment for security. Older children require periodic assurance and adolescents are still less needful of parental presence. This attachment continues to change as the adolescent grows up and begins an independent life and family of her own. Therefore, it is reasonable to assume the impact of a mother developing breast cancer may differ for an adolescent daughter compared to a daughter in her thirties. One study reported that women seeking genetic testing who had lost their

mothers during impressionable teenage years had grown to be more resentful of both their family history as well as their own breasts and bodies than daughters who were in their twenties when their mother died from cancer. (Biesecker et al., 1993). Wellisch, Gritz, Schain, Wang, and Siau (1991) reported that adolescent daughters of mastectomy patients experienced increased psychosomatic problems. In a follow-up study, they also hypothesized that the age of the daughter when her mother developed breast cancer would be related to her lack of resolution about the illness, lack of sexual intimacy, and present emotional symptomatology (Wellisch, Gritz, Schain, Wang, & Siau, 1992). Daughters who were adolescents during their mother's illness had significantly greater feelings of discomfort about her illness than those who were in early childhood (1-10 years old) or adulthood (20 years and older). Daughters who felt that their roles and life plans had changed due to their mother's illness reported more difficulty adjusting to their mother's cancer. There is also a difference in the level of distress reported based on whether mothers survived or died from cancer. Erblich, Bovbjerb, and Valdimarsdottir (2000) reported that daughters with family histories of breast cancer whose mothers had died of the disease experienced more distress, including intrusive thoughts and avoidant behavior, than those women whose mothers survived.

Based on the work of Brown and Harris (1989) and the family affiliation literature (Moore, 1990), it is reasonable to assume that daughters tend to have a greater attachment to their mothers. Rossi and Rossi (1990) stated that same sex-dyads of mothers and daughters display greater intimacy, interaction, and exchange of help than father-daughter dyads. They are also more likely to have a greater affiliation with other female relatives

(i.e., sisters, aunts, grandmothers) than male relatives. Fenchel (1998) found that women have a necessary interdependence on other women and rely strongly on each other for support. Even though fathers are important in female development, mothers have an integral role in their daughter's lives and have significant influence on the shaping of their daughters' identity. Therefore, a female relative diagnosed with cancer may have a stronger impact on women than a male relative. A study of 249 women conducted in London found that the loss of a mother before the age of 17 years was found to double the risk of depression and anxiety disorders in women as an adult (Bifulco, Harris, & Brown, 1992). However, loss of a father by age 17 years was not associated with adult depression in women (Harris, Brown, & Bifulco, 1986). In addition, a woman may feel more threatened or vulnerable to female cancers (i.e., breast and ovarian cancer) than to other non-gender specific cancers. Therefore, a mother diagnosed with breast or ovarian cancer may result in an increase in psychological distress in daughters compared to a father diagnosed with prostate cancer.

Tend-and-Befriend Response to Stress in Females

Being at high-risk for cancer, as well as experiencing family members with the disease, can be very stressful. This stress may be chronic and life-long. Recently, there have been studies suggesting that males and females may respond differently to stress (Taylor et al., 2000). The generic fight-or-flight response proposed by Walter Cannon (1932) may actually be more of a male phenomenon than a female response. This fight-or-flight metaphor represents a human behavioral response to stress in which a human (or animal) fights or flees in response to a threat. When under stress, the body elicits a

hypothalamic-pituitary-adrenocortical (HPA) response. Sympathetic arousal due to norepinephrine and epinephrine released in the bloodstream prepares the body for attack. Most stress research, however, has been conducted on male animals and humans (Gruenewald, Taylor, Klein, & Seeman, 1999). It is possible that males and females react differently when experiencing this sympathetic arousal.

Taylor and colleagues (Taylor, Klein, Lewis, Gruenewald, Gurung, & Updegraff, 2000) proposed that females respond to stress with a pattern termed "tend-and-befriend" (p.3). Numerous stress hormones including corticotropin-releasing factor (CRF), vasopressin, and oxytocin are released in response to a stressor. These hormones further stimulate the release of adrenocorticotropin hormone (ACTH) from the anterior pituitary. As a result, cortisol is released into the body. Historically, males have displayed increases in aggression in response to the release of these stress hormones (Girdler, Jamner, & Shapiro, 1997). Female hostility, however, is not as reliably linked to sympathetic arousal. This led Taylor and her colleagues to the hypothesis that perhaps the fight-or-flight response may be more gender specific than once believed.

The "tend" portion of this new theory is partially derived from attachment theory (Bowlby, 1988). Under times of stress, the female tending response of caring for offspring seems to increase (Hofer, 1995). For example, Repetti (1997; 2000) reported that women were more nurturant and caring toward their children on days in which they reported the most stress at work. In adulthood, oxytocin released in response to stress has been noted to be stronger for females than males and may be at the core of this tending response (Pankstep, Nelson, & Bekkedal, 1999). This release of oxytocin has been

hypothesized to have two functions. It may produce a calming effect for physiological arousal in females as well as promote affiliative behaviors, including maternal behaviors (Taylor et al., 2000).

This tend response is in relation to increased nurturing of offspring and family when experiencing stress. Therefore, it is reasonable to examine family environments of women reporting distress, a predictor of elevated levels of life stress. The role of the family in mediating an individual's development and adjustment has been studied extensively in the past three decades. Studies have examined the way families interact, share information, and communicate with each other. Family research has indicated that there are many different family environments and ways in which family members relate with each other.

The families of women with personal cancer history and a family history of cancer may organize themselves and have different needs than families without a cancer history. It is also possible that these women exhibit the proposed "tend" response, displaying a stronger need for nurturance and cohesion in their families. One study examining family styles reported that women with breast cancer have a higher need for family cohesiveness and closeness that goes beyond the norm for medically healthy women (Friedmen et al., 1988). In fact, women who reported greater adjustment to breast cancer also reported the highest levels of cohesiveness. In many cases, this familial cohesiveness was so high, it would be classified as dysfunctional by the Circumplex Model of Family Systems which examines cohesion and adaptability in families (Olson, Sprenkle, & Russell, 1979).

Another study examining family relationships of women with metastatic breast cancer found that less mood disturbance and lowered distress was predicted by more expressiveness and less conflict and less moral-religious orientation (Spiegel, Bloom, & Gottheil, 1983). This expressiveness was described as sharing and expressing emotions and needs with family members. Many women who present for genetic testing for BRCA1 and BRCA2 mutations have family cancer histories, and may present with a personal cancer history as well. The stress of witnessing loved ones suffer with cancer and the psychological distress which results from perceiving oneself to be at high-risk for developing cancer or a cancer recurrence, may have an effect on the development and structure of interpersonal relationships.

Along with the nurturing "tend" response to stress, Taylor et al. (2000) proposed that females also display a tendency to "befriend" when experiencing sympathetic arousal (p. 20). Befriending refers to the tendency to affiliate with others when experiencing stress by developing or reaching out to a support network. Cohen and Wills (1985) proposed that social support provides a buffer mitigating the emotional impact of stressful events. In the case of women with breast cancer, social support has widely been associated with better overall psychosocial functioning (Irvine, Brown, Crooks, Roberts, & Browne, 1991). According to House (1981) social support may alleviate the impact of a stress experience by reducing the importance of the perception that a situation is stressful or it may somehow "tranquilize" the neuroendocrine system so that one is less reactive to stress. Finally, social support may facilitate helpful behaviors and help to generate possible solutions and alternatives (Cohen & Syme, 1985). In support of their

theory, Taylor et al. (2000) cited research showing that when under stress, females display a stronger desire to affiliate than males and tend to affiliate more with other females during times of stress than with males (Lewis & Linder, 2000; Schachter, 1959).

Studies have addressed the benefits of social support for high-risk women, but relatively few have systematically examined support networks. Coyne and Anderson (1999) explored the support processes for women seeking genetic testing who are at high-risk for breast and/or ovarian cancer. In general, women experienced greater levels of distress as a result of perceiving less social support. Support from spouse was positively correlated with support from a close female relative, both of whom were important. Interestingly, women in satisfactory marriages actually perceived more support from female relatives than did unmarried women or women in unsatisfactory marriages. For cancer-specific support (i.e., discussing fear of cancer, exploring possible treatment options and testing), sisters were found to be very important. Little subsequent research has examined social support networks for women seeking genetic testing. The gender and relationship of friends versus family members of women's support networks may be related to perceived satisfaction with support. Another important unanswered question is the identity of those on whom women rely on for support (e.g., mother, father, sister, friend) and if the networks differ based on whether or not the women have a personal or family cancer history.

Summary

Research has begun to identify shared characteristics of women seeking genetic testing for breast and ovarian cancer. A family history of breast and/or ovarian cancer

may increase levels of psychological distress. As genetic testing becomes more commercially available for BRCA1 and BRCA2 mutations, it is important that research continue to identify predictors of psychological distress in women seeking genetic testing. Understanding factors that may exacerbate and alleviate this distress may lead to efficient and appropriate interventions for these high-risk women seeking genetic testing. Consequently, the proposed study will further explore patterns of distress by examining relationships. Family interactions and environments will be examined because certain family characteristics may be related to psychological distress. Examining support networks will also provide insight into the connection between relationships and psychological distress. It is important to critically examine the identity of the individuals comprising these networks and the role they may have in alleviating distress. Finally, by studying family environments as well as support networks, patterns can be examined to provide behavioral evidence for the proposed tend-and-befriend female response to stress, in which women display increased affiliative and nurturing behaviors when reporting distress, a reflection of stress.

Clinically, it is also very important to identify factors that contribute to elevated levels of psychological distress. As previously mentioned, high levels of distress impedes surveillance behaviors and preventative care such as breast self-examinations and mammography. Prolonged stress also compromises the immune system. Women, particularly those with personal cancer histories, need their immune systems to be as strong as possible to endure not only the disease, but the treatments as well. By identifying affiliative patterns that may alleviate distress, these women can be targeted

early for intervention and counseling. Increased distress also decreases the reported quality of life for these women. Through support networks and family interactions, distress can be minimized, hence improving overall satisfaction with one's life.

Hypotheses

1. Women with a personal cancer history will report more family cohesiveness indicated by higher means on the cohesion subscale and a greater than chance classification as support-oriented families.
2. Women whose mothers were diagnosed with cancer when women were adolescents (11-19 years of age) will report greater distress than those who were children (1-10 years) or adults (20 years and up) when their mothers were diagnosed.
3. Women with first-degree female relatives with breast and/or ovarian cancer will have higher levels of distress than women without first-degree female relatives with breast and/or ovarian cancer. These women will also have higher levels of distress than women with first-degree male relatives with cancer.
4. There will be more females than males in the network when examining first-and second-degree relatives in the social support network.

Research Questions to Test Hypotheses:

H1a. Are there differences between family types of women with first-degree relatives with breast and/or ovarian cancer compared to women without a history of first-degree relatives with breast and/or ovarian cancer?

b. Are there differences in reported family types for women with a personal cancer history versus women without a personal cancer history? Are there differences on the 10 Family Environment subscale mean scores for women with a personal cancer history versus women without a personal cancer history?

H2a. Are there any differences in total psychological distress by the three developmental stages of age of participant when a first-degree relative was diagnosed with any cancer?

b. Does total psychological distress vary based on the type of cancer first-degree female relatives report (breast cancer versus ovarian cancer versus other cancers)?

H3. Are there differences in reported psychological distress based on male versus female first- and second-degree relatives diagnosed with any cancer?

H4.a. When examining both first- and second-degree relatives in the support networks, are there more females in the network than males?

b. Do women with more females in their support network report greater mean social support satisfaction?

<u>Exploratory Family History Research Questions:</u>

1. Are there differences in psychological distress between those with at least one first-degree relative with breast and/or ovarian cancer compared to those without any first-degree relatives with breast and/or ovarian cancer? This will be compared for individuals with and without personal cancer histories.

2. Are there differences in psychological distress between women whose mother versus father died from cancer compared to women whose mother versus father survived cancer?

Exploratory Social Support Research Questions:

3. Do women with first-degree relatives with breast and/or ovarian cancer rely proportionately more on family versus friends than women without first-degree relatives with breast and/or ovarian cancer? Do women with first-degree relatives with breast and/or ovarian cancer rely more on females than males for support than women without first-degree relatives with breast and/or ovarian cancer?

4. Are there differences in mean social support satisfaction for women with first-degree relatives with breast and/or ovarian cancer compared to women without a first-degree relative with breast and/or ovarian cancer? Are there differences on mean social support satisfaction for women with a personal cancer history compared to women without a personal cancer history?

5. Are there differences in mean social support satisfactions based on reported family type?

6a. Do women reporting greater distress report a larger number of individuals in their support network?

b. Do the number of females in the social support network relate to mean social support satisfaction? Does the proportion of females in the social support network relate to mean social support satisfaction?

7. Is there an interaction (combination) of number of individuals in the social support network and family type that predicts greater psychological distress?

Exploratory Family Environment Research Questions:

8. What do the family environments of self-referred genetic testing participants look like?

9. What are the reported family types for Ashkenazi Jewish women?

10a. Are there more support-oriented families than each of the other six types of families?

b. Are the family environment subscale means for cohesiveness and expressiveness higher for this sample when compared to normal and distressed families provided in the manual?

11. Do support-oriented families report higher levels of distress than the six other family types?

CHAPTER II

METHOD

Participants

The participants were either self-referred or participated in genetic screening based on a physician's referral or recommendation. All participants met the requirements for the Baylor University Medical Center (BUMC) Cancer Registry for the Breast Cancer Risk Evaluation Program (BCREP). These requirements are that participants be at least 18 years of age, along with no prior history of a pre-existing psychological condition (i.e. clinically significant conditions such as depression and anxiety).

Of the 66 women who enrolled in the study, 51 (77.2%) remained in the study and had a second visit. Ethnicity was primarily Caucasian (n = 48, 94.1%) with eight (15.7%) women self-identifying as Ashkenazi Jewish. The mean age was 45.5 years (range = 28.3 to 76.9 years old; SD = 12.34). At the time of the study, 41 women (80.4%) reported being married, one (2%) divorced, two (3.9%) widowed, and seven (13.7%) identified themselves as single. Education ranged from a high school diploma to professional school training. Six (11.8%) reported earning a high school diploma, 12 (23.5%) had at least some college, 21 (41.2%) had a college degree, and 12 (23.5%) reported graduate or professional school degrees. Thirty-seven women (72.5%) were currently employed.

Of these 51 participants, 43 (84%) completed genetic testing and received results. There are many reasons why women withdraw from testing. For some, health insurance providers deny coverage of the genetic testing resulting in an out-of-pocket payment of over two thousand dollars. After receiving objective risk data at their initial visit (based

on genetic counseling pedigree), some decide the risk is not as elevated as once thought and decide to wait on testing. Finally, a woman can have her mother and/or father tested for the genetic mutation. If the parents are negative, the woman is at a decreased risk of being a genetic mutation carrier and may choose to withdraw from testing. Regardless, all 51 women who presented for a second visit and completed measures initially came to this appointment due to a perception of being at high-risk, primarily due to a personal or family cancer history and will be included in these analyses.

Over half of the participants (n = 31, 60.8%) reported a personal cancer history. Thirty-nine participants (76.5%) reported a history of breast problems. Thirty-seven women reported having a breast biopsy with a mean of 1.31 biopsies (SD = .51, range = 0 to 5). Thirty-five (69.6%) reported having at least one first-degree relative with breast and/or ovarian cancer. For the sample, the mean number of first-degree relatives reported with cancer was 1.49 (SD = .99, range = 0 to 4). The mean number of second-degree relatives with any cancer was 2.29 (SD = 1.79, range = 0 to 7). Finally, the mean total number of relatives with any cancer was 3.78 (SD = 2.0, range = 1 to 9). All descriptive data are presented in Tables 1 and 2.

Procedure

All women were provided with genetic screening education. During their initial visit, women were also educated about this study and provided with the option to participate. Approximately half of the women who presented for an initial visit agreed to participate in this study. All participants provided informed consent and were allowed to withdraw from the study at any time.

Participants received five separate packets of questionnaires designed to measure perceived risk, psychological distress, coping style, quality of life, social support, family environment, and the impact of the risk notification process. The first packet corresponded with the initial visit in which the participant met with a genetic counselor and was educated about genetic testing. During this initial visit, they were provided with objective risk data based on their family cancer history. The second packet corresponded with the second visit to the genetic counselor in which blood was drawn for the genetic test. The third packet was given to women after their third visit when they received their genetic test results. The fourth packet was mailed to participants approximately three months following the receipt of genetic results. Finally, the fifth packet was mailed approximately six months following the fourth visit (nine months after the participant received her genetic test results). Some participants had their blood drawn at the initial visit. In this case, they received a first visit packet of questionnaires that combined both visits one and two. This study will use measures associated with the second visit in which the participant had her blood drawn and had not yet received test results. Data was collected from July 1998 through July 2000.

Measures

Demographic Information. All demographic information was obtained using the Baylor University Medical Center (BUMC) Registry intake form. This information was then transcribed to the demographic form used specifically for this study. This form included information regarding age, marital status, education, personal cancer history, and number and relationship of first- and second-degree relatives who had cancer.

Participants also reported age of diagnosis, age of death (if applicable), and type of cancer for these first-and second-degree relatives. See Appendix A for this measure.

Psychological Distress. The Hopkins Symptom Checklist (HSCL) was used to measure psychological distress (Derogatis, Lipman, Rickels, Uhlenhuth, & Covi, 1974). See Appendix B. The scale consists of 58 items scored on a four-point Likert-type scale anchored by not at all (1) and extremely (4). Factor analyses resulted in the five dimensions of Somatization, Obsessive-Compulsive, Interpersonal Sensitivity, Depression, and Anxiety (Derogatis et al., 1974). The alpha internal consistency reliability of the HSCL has been reported at .87 in a sample of 1,435 outpatients. Overall score was computed as the mean of all items. Subscale scores were computed as the mean for items contained in that factor. Both total distress as well as the five subscales will be used in analyses.

Social Support. Social Support Questionnaire-6 (SSQ6) was utilized to measure social support (Sarason, Sarason, Shearin, & Pierce, 1987). This measure was developed from the 27-item Social Support Questionnaire (SSQ; Sarason, Levine, Basham, & Sarason, 1983). Both the SSQ and the SSQ6 yield scores for perceived number of social supports as well as satisfaction with social support. See Appendix C. The number score is the mean number of social support persons listed. The satisfaction score is a mean score for all of the people listed and is reported on a scale ranging from very dissatisfied (1) to very satisfied (6). The SSQ was normed on a sample of 602 undergraduates. Inter-item correlations range from .21 to .74 ($\underline{M}$ = .54). The alpha correlation for satisfaction scores was .94. The correlation between the social support number scores and the satisfaction

scores was .34. The test-retest correlations for a 4-week interval for number and satisfaction scores were .90 and .83 respectively. Factor analysis revealed the highest six loadings which were chosen to comprise the SSQ6. For three independent samples, internal reliabilities for number were between .97 and .98 and between .96 and .97 for satisfaction. This test was found to be psychometrically comparable to the SSQ.

Family Typology. The Family Environment Scale (FES)-Form R was utilized to obtain information on family relationships (Moos & Moos, 1986). This is a 90-item true/false questionnaire which measures perceptions of conjugal or nuclear family environments. Research sought to identify unifying dimensions of family interaction, but Billings and Moos (1982) argued that research should simultaneously consider several dimensions. Typologies from the Family Environment Scale (FES) consist of several dimensions of family relationships. Means are provided for the ten FES subscales and can be compared to norms provided in the manual for "normal" versus "distressed" families. Based on the mean scores for these subscales, the three dimensions are Relationship, Personal Growth, and Systems Maintenance. The Relationship dimensions are measured by the Cohesiveness, Expressiveness, and Conflict subscales. The Personal Growth dimensions are measured by the Independence, Achievement Orientation, Intellectual-Cultural Orientation, Active-Recreational Orientation, and Moral-Religious Emphasis subscales. Finally, the Systems Maintenance dimensions are measured by the Organization and Control subscales. Along with the three family environment dimensions, the ten subscales also are used to create seven mutually exclusive family types. For Personal Growth-Oriented families, the corresponding family types are

Independence-Oriented, Achievement-Oriented, Moral-Religious Oriented (Structured and Unstructured), and Intellectual-Cultural Oriented. For the Relationship-Oriented families, the corresponding family types are Support-Oriented families and Conflict-Oriented families. Finally, the System Maintenance-Oriented family is comprised of Disorganized families.

Form R of the FES was normed on 1,125 normal and 500 distressed families. Internal consistency for the ten subscales was in the moderate range from .61 for Independence to .78 for Cohesion, Intellectual-Cultural Orientation, and Moral-Religious Emphasis. The test-retest reliabilities over an eight-week interval were all in the acceptable range, varying from a low of .68 for Independence to a high of .86 for Cohesion. There was also a mean four-month profile stability for families of .78. Construct validity was supported through several family studies (Brown, Yelsma, & Keller, 1981; Sandler & Barrera, 1984; Swindle, 1983; Waring, McElrath, Lefcoe, & Weisz, 1981).

CHAPTER III

RESULTS

An attrition analysis was performed comparing the 51 women who completed both the first visit and second (blood draw) visit with the 15 women who dropped out of the program after the first visit and did not have blood drawn. These groups did not differ on marital status, χ^2 (3) = 3.27, $\underline{p}$ =.29; ethnicity, χ^2 (2) = .92, $\underline{p}$ = .63; education, $\underline{t}$ (64) = .48, $\underline{p}$ = .64; number of biopsies, $\underline{t}$ (64) = 1.25, $\underline{p}$ = .22, performing self-breast examination, χ^2 (1) = .03, $\underline{p}$ = .68, confidence with breast self-examination, χ^2 (1) = .02, $\underline{p}$ = .89, and by having first-degree relatives with breast and/or ovarian cancer, χ^2 (3) = 2.16, $\underline{p}$ = .54. Differences were found on personal cancer history, χ^2 (1) = 10.44, $\underline{p} < .001$, and history of breast problems, χ^2 (1) 4.88, $\underline{p} < .03$. More women with a personal cancer history ($\underline{n}$ = 31, 60.8%) or a reported history of breast problems ($\underline{n}$ = 39, 76.5%) remained in the study and proceeded with genetic testing.

The first hypothesis examined family type differences for women with and without first-degree relatives with breast and/or ovarian cancer, predicting women with a first-degree relative with breast and/or ovarian cancer would be more likely to be categorized as support-oriented families. For the 51 participants, only 36 (70.6%) met the requirements and were classified into a family type. Eight participants (15.7%) were classified as Independence-Oriented, four (7.8%) were Achievement-Oriented, twenty (39.2%) were classified as Structured Moral-Religious Families, two (3.9%) were Unstructured Moral-Religious, and two (3.9%) were Support-Oriented. Only five of the seven family types were found in this sample. There was no significant difference in

family type for women with and without first-degree relatives with breast and/or ovarian cancer, χ^2 (4) = 3.23, $\underline{p}$ = .52. Frequencies of the five family types for these different subgroups are provided in Table 3. Although the cell sizes were small for this comparison, the results were retained because Chi Square is a nonparametric statistic and there was no appropriate alternative statistic to use for comparisons.

The second part of Hypothesis 1 addressed family types for women with and without personal cancer histories. Once again, family type did not significantly differ for these groups, χ^2 (4) = 8.95, $\underline{p}$ = .06 (Data in Table 3). These results however approached significance, with more Independence-Oriented families among women with a cancer history and more Achievement-Oriented families among women without a cancer history. With a larger sample size, a difference may be revealed.

One possibility is that a personal cancer history is associated with scores on the Family Environment Scale (Moos & Moos, 1986). To address this possibility, a MANOVA was conducted on the ten subscales. There was a small effect size (.30) and the MANOVA was not significant, $\underline{F}$ (10,38) = .70, $\underline{p}$ = .72. None of the associated t-tests approached significance with findings ranging from $\underline{p}$ = .17 (Control) to $\underline{p}$ = .99 (Active-Recreational). As can be seen in Table 4, the means and standard deviations for women with and without a personal cancer history were quite similar on all subscales.

Hypothesis 2 addressed differences in psychological distress by the three developmental stages at which participants' first-degree relative was diagnosed with any cancer. Women who were adolescents were expected to report more psychological distress than women who were children or young adults when their parents were

diagnosed. This ANOVA was not significant, F (2,33) = .012, p = .99, partly due to group size. Only two women were children (1-10 years old) and six were adolescents (11-19 years old). Most (n = 28) were adults when their parent(s) were diagnosed with cancer. Difference between the mean psychological distress scores, however was very small for the three groups of women who were children (M = 1.51, SD = .09), adolescents (M = 1.47, SD = .23), and young adults (M = 1.48, SD = .34).

The second part of Hypothesis 2 examined total psychological distress by type of cancer reported in first-degree relatives; breast cancer (n=31) versus ovarian cancer (n=1) versus other cancers (n=9). Due to few first-degree relatives being diagnosed with only ovarian cancer, the comparison was run for breast and ovarian cancer (M = 1.47, SD = .34) versus other cancers (M = 1.44, SD = .27). This comparison was not significant, t (39) = .25, p = .81.

Continuing to explore family cancer history and psychological distress, Hypothesis 3 addressed differences in psychological distress based on the gender of first- and second-degree relatives diagnosed with any cancer. It was predicted that the presence of more female relatives diagnosed with cancer would be related to psychological distress. A linear regression analysis was conducted and gender of first- and second-degree relatives was not predictive of psychological distress, adj R^2 = .01, F (4, 45) = 1.17, p = .34.

The fourth and final hypothesis addressed two issues. First, were there more females than males in the social support networks of women participating in this community genetic testing project? Second, did satisfaction with social support vary

based on the gender of the provider? It was predicted that there would be more females in the social support networks of these participants. For the first and second analyses, five and eight (respectively) participants were excluded due to missing data on gender of support provider and satisfaction rating. A t-test showed significantly more females (M = 2.20, SD = 1.31) than males (M = 1.37, SD = 1.06) in the support networks of these women, t (45) = 3.61, p < .001. Social support satisfaction, however, was not significantly related to the gender of the provider, t (42) = .90, p = .37. Having more females in the social support network (M = 5.28, SD= 1.07) than males (M = 5.52, SD = .49) was not related to satisfaction with the support provided. It was noted that the social support satisfaction mean distribution was not normal, with a majority of participants reporting high satisfaction with support providers. Log transformation and mean trimming were performed, however there was no improvement to this skewed distribution.

Two research questions further explored family history and its association with psychological distress. First t-tests compared women with first-degree relatives with breast and/or ovarian cancer to women without first-degree relatives with breast and/or ovarian cancer on all five HSCL subscales of distress as well as total HSCL distress. None of the six analyses in Table 5 were significant. The presence of a personal cancer history was also unrelated to women's psychological distress. These analyses are shown in Table 6.

Research Question 2 proposed differences in psychological distress between women whose mother versus father died from cancer compared to women whose mother

versus father survived cancer. This analysis could not be conducted using parametric statistics due to a group sizes. One women's mother died from cancer, five women had fathers die from cancer, and seven reported both parents having died from cancer. Thirty-eight participants reported both parents still living. Nonparametric statistics require less stringent assumptions of the data and can be used with small sample sizes. The Kruskal-Wallis test, a nonparametric alternative to the ANOVA, was used to analyze psychological distress differences for the above groups of women who had a parent die from cancer. The results were not significant, χ^2 (3) = 3.27, $\underline{p}$ =.29.

Five research questions addressed women's social support networks in association with relatives' cancer history, personal cancer history, and family type. Table 7 shows characteristics of the current sample of women's support networks. For Research Question 3, the number of relatives and friends was transformed into two categories as having more relatives than friends or having more friends than relatives. Women with first-degree relatives with breast and/or ovarian cancer did not report more relatives than friends in their support networks than did women without first-degree relatives with breast and/or ovarian cancer, χ^2 (1) = .92, $\underline{p}$ = .60. Overall, however, the entire sample of women reported that they relied significantly more on relatives ($\underline{M}$ = 4.39) than friends ($\underline{M}$ = 2.65), $\underline{t}$ (45) = 4.08, $\underline{p}$ < .001. Gender within this sample's support networks was also addressed. Participants with first-degree relatives with breast and/or ovarian cancer were not more likely to rely on females rather than males for support, χ^2 (1) = .88, $\underline{p}$ = .58.

Research Question 4 addressed social support satisfaction as associated with first-degree relative cancer history and personal cancer history. Neither analysis was significant. Social support satisfaction does not differ for those with (M = 5.53, SD = .56) or without (M = 5.36, SD = .94) first-degree relatives with breast and/or ovarian cancer, t = (46) = .65, p = .52. Similarly, participants with (M = 5.42, SD = .96) and without (M = 5.39, SD = .63) a personal cancer history, did not differ on satisfaction with support t (46) = .15, p = .89. Once again it was noted that the distribution of support satisfaction means was skewed.

Research Question 5 was to explore differences in social support satisfaction for the different family types. As mentioned previously, only 36 (70.6%) of the 51 participants met the requirements and were classified into a family type. Social support satisfaction was not related to family type, F (4,29) = .17, p = .95. This analysis was also conducted using nonparametric statistics (Kruskal-Wallis test) due to small group size, with results that were not significant, χ^2 (4) = 2.12, p = .71.

Research Question 6 addressed the association of psychological distress with the number of individuals reported in social support networks and gender of support provider. As shown in Table 8, none of the correlations reached significance. There were also no significant relationships between the number of female support providers and social support satisfaction (r = .09, p = .54).

For Research Question 7, an ANCOVA was utilized to examine the association of family type on psychological distress. The number of individuals reported in the support

network was used as a covariate. No significant difference was found, F (4,33) = .95, p = .34.

Research Questions 8 and 9 addressed participants' family environment. As reported previously, only 36 out of the 51 participants were classified into a family type. Also, only five out of the seven family types were found in this sample. Thirty-four out of the 36 classified families were Personal Growth Oriented Families, while only two were Relationship Oriented Families. Means for each subscale are listed in Table 9.

For the eight Ashkenazi Jewish women in this sample, six were classified into family types (Research Question 9). Four women were classified as Independence-Oriented families, one woman was classified as Achievement-Oriented family, and one as a Support-Oriented family. Means and standard deviations for the ten family environment subscales were used to create a z-score for mean comparison. The current sample of Ashkenazi Jewish women (n = 8) was compared with normal families (n = 1,125), distressed families (n = 500), whose subscale means and standard deviations were provided in the Family Environment Scale Manual (Moos & Moos, 1986) for significant differences. A z-score was obtained for each subscale and compared to a critical value to determine significance. Although the subscale means for both normal and distressed families include responses from both males and females, there are no significant gender differences in the perception of family environments; hence it is a valid comparison. Means and z-scores for the ten family environment subscales for Ashkenazi Jewish women in this study are presented in Table 10.

Ashkenazi Jewish women had significantly less cohesion ($Z = -2.04$, $p < .05$) than normal families. They did not significantly differ from cohesion subscale scores for distressed families ($Z = .86$, $p > .05$). The expressiveness subscale mean was not significantly higher than normal families ($Z = 1.00$, $p > .05$) but was significantly higher than distressed families ($Z = 2.26$, $p < .05$). Finally, moral-religious subscale means were significantly lower than both normal families ($Z = -2.45$, $p < .05$) and distressed families ($Z = -2.20$, $p < .05$).

Research Question 10 addressed the family environments of the entire sample. There were not more support-oriented families ($n = 2$) than other types of families. Interestingly, there were significantly more moral-religious families ($n = 22$) than the remaining 4 types combined, $\chi^2 (2) = 21.55$, $p < .001$.

The second part of Research Question 10 compared the family environments of these community women seeking genetic testing with family environments of normal and distressed families. Once again, z-scores were calculated using the means and standard deviations for normal families ($n = 1,125$), distressed families ($n = 500$), and the current total sample of genetic testing participants ($n = 51$). The obtained z-score was then compared to a critical value to determine significance. Means and obtained z-scores are provided in Table 11. There were several significant differences between this sample of women seeking genetic testing and both the normal and distressed families. Most importantly, the subscale means for cohesion ($Z = 4.84$, $p < .001$; $Z = 8.93$, $p < .001$) and expressiveness ($Z = 2.59$, $p < .01$; $Z = 5.68$, $p < .001$) were significantly higher in this sample than both the distressed and normal groups in the Moos and Moos (9186) study.

The last Research Question addressed the relationship between Support-Oriented families and psychological distress. Due to a small group size, nonparametric statistics were used to comparison Support-Oriented families ($n = 2$) with the other four family types ($n = 34$). The Mann-Whitney test, the most common nonparametric alternative for an independent samples t-test, was used and yielded nonsignificant results ($p = .08$). T-tests were conducted, however to reveal any differences in psychological distress between all five family types. No significant differences were found. These means and standard deviations are shown in Table 12.

CHAPTER IV

DISCUSSION

Testing for BRCA1 and BRCA2 genetic mutations has recently become commercially available. Consequently, little systematic research has examined characteristics of women who present to community genetic testing programs. This present research was one of the first exploratory studies to systematically examine affiliative behaviors of community women seeking BRCA1 and BRCA2 testing. For psychological distress, there were no significant differences associated with family cancer history, personal cancer history, composition of social support network, or family environment. The number of female versus male relatives diagnosed with cancer did not impact the level of psychological distress reported. The type of cancer reported within one's family history also did not impact psychological distress in this sample. Although interpreting null results should be done with caution, as discussed in limitations, these findings correspond with Lerman et al.'s (1997) study that also did not find a relationship between the number of first-degree relatives with breast and ovarian cancer and psychological distress.

Despite the fact that psychological distress did not differ for those with and without first-degree relatives with breast and ovarian cancer, this information is still useful. There are many combinations of family and personal cancer history within the genetic testing participants in this study. Whether a person has one or ten relatives with cancer may be irrelevant when examining psychological distress. Perceived risk of having a genetic mutation and/or developing cancer, however, may be an important

component. Objective risk status may be significantly lower than perceived risk, but perception may be reality for all of these women and research has been consistent stating those who present for genetic testing overestimate the likelihood they will develop cancer (Lerman et al., 1995). Education and counseling regarding objective risk status is very important in the beginning of the risk notification process. Health care professionals need to be sensitive to concerns and fears of these women. Assisting participants in understanding and comprehending both objective risk status as well as the implications of a positive result may be a crucial component to helping these women cope with the genetic testing process and with their fears of cancer.

The hypothesis that social support networks for this sample of women seeking BRCA1 and BRCA2 genetic testing would consist more of females than males was supported. These findings may not tell us if this is a characteristic specific to these at-risk women, but the findings do correspond with Taylor et al.'s (2000) research. The fact that females in this study tend to turn to other females supports the contention that females may exhibit particular affiliative behaviors when experiencing stressful situations. More research should be conducted to truly differentiate this as a gender specific response.

This sample also relied more on relatives than friends for support. This is a reasonable finding based on the population being sampled. Most of the women in this study reported a family cancer history. Genetic based cancers have an impact on the entire family, not just a single member. Women in this study may be looking for guidance and support from other family members who have been diagnosed with cancer.

They are also becoming aware of the implications of a positive genetic mutation for their children and future generations.

Reported satisfaction with support provided, however was not related to the gender of the provider. Satisfaction was similar for participants who had more women in their support network as that reported by participants who had the same number of men and women, or more men in their network. Mean satisfaction scores were very similar; therefore this may not be a result of small sample size. Limitations in the format of the social support questionnaire may have hindered these analyses.

There were several interesting findings regarding the family environments of women in this sample. Comparisons of women with and without a personal cancer history approached significance indicating a trend for women with a personal cancer history to report more Independence-Oriented families than women without a personal cancer history. According to Moos and Moos (1986), this family type contains members who are assertive and self-sufficient. Having a family member diagnosed with cancer often changes the structure and interactions of family members. Responsibilities that were once taken care of by one member are delegated to other family members. An individual who is ill or participating in demanding treatments such as radiation and chemotherapy often does not have the strength to provide the level of care taking that they once did. This shifting of responsibilities often demands that family members become more autonomous to allow the member who is ill to focus limited energy on treatment.

When examining family breast and/or ovarian cancer history, there were no differences in family environments for women with and without a family history. The sample as a whole, however report significantly more cohesion and expressiveness in their family interactions when compared to data from normal and distressed families (Moos & Moos, 1986). All women in this study who presented for genetic testing had either a personal cancer history or a first- and/or second-degree relative(s) with cancer. Also, in general women who present for BRCA1 and BRCA2 genetic mutation testing generally perceive themselves to be at high-risk for cancer and report thoughts of cancer intruding into their daily lives (Bluman et al., 1999). These significantly elevated levels of cohesion and expressiveness in this sample correspond with other studies of women who have had their lives affected by cancer (Friedmen et al., 1988).

All except two women were classified as having Personal Growth Oriented Family types. This classification includes Independence-Oriented Families, Achievement-Oriented Families, and Moral Religious-Oriented Families. Typically those who are classified as Personal Growth Oriented families tend to display assertiveness, higher self-esteem, and recognition of personal needs within family interactions (Moos & Moos, 1986). More interestingly, subscale scores of the Family Environment Scale have been found to be predictors of distress. For this sample, cohesion and expressiveness were significantly higher than normal families and conflict was significantly lower. This pattern of relating has been predictive of an increased ability to cope, especially in dealing with physical illness (Moos & Moos, 1986). These high levels of cohesion and expressiveness have also been linked to improved adjustment to cancer (Friedman et al.,

1988). In general, high cohesion and expressiveness paired with low conflict is a supportive family environment. This manner of interacting with family may act as a moderator for distress. It is possible that the family environments of these at-risk women are buffering the psychological effects of having cancer (or a family cancer history) and/or the genetic risk notification process. Health care professionals (physicians, genetic counselors, nurses, psychologists) should encourage community women seeking genetic testing to utilize their families for support and guidance through the risk notification process. This support network is a major asset for these women.

Moos and Moos (1986) also reported an inverse relationship between moral-religious subscale scores and distress. Higher moral-religious scores have been associated with decreased reported distress. The women in this study had significantly higher moral-religious scores than normal families. Twenty-two of the 36 families classified were Moral-Religious-Oriented. These findings may be explained several ways. There may be a shared religious characteristic among at-risk women, relating to their family and/or personal cancer histories. Religion may be used as an attempt to cope with being diagnosed with cancer or observing a loved one suffer. Second, the emphasis on ethical and religious issues and values may be influenced by demographic characteristics, specifically social class. The majority of participants were Caucasian, well-educated women. Commercial genetic testing is also relatively new and can be expensive. Individuals desiring tests either have health insurance or have the financial resources to pay the costs. This leads to the assumption that this type of testing attracts more affluent individuals. There may be a relationship between the socioeconomic status of these

participants and their moral-religious orientation. Finally, these findings may also be geographically influenced. The South is known for its strong religious beliefs ("Bible Belt"). It is possible that a sample matching this one taken from another geographic location would not exhibit such moral-religious tendencies.

Only limited analyses were conducted for the family types of Ashkenazi Jewish women. Some interesting findings were revealed when the family environment subscale means for the eight Ashkenazi Jewish participants were compared with those of multi-ethnic normal and distressed families (Moos & Moos, 1986). Women in this study who were of Ashkenazi Jewish descent were significantly lower on both cohesion and moral-religious subscales than normal families. Even when compared to distressed families, their means were significantly lower. These findings are predictive of increased psychological distress and depression (Moos & Moos, 1986). This supports past research that has shown women of Ashkenazi Jewish descent are not only objectively at higher risk for a BRCA1 and BRCA2 genetic mutation, but also exhibit increased psychological distress (Lesniak, 2000). The implications of these findings are that Ashkenazi Jewish women seeking genetic testing should be identified for intervention to help them cope with the risk notification process. These women, in general, do not have the supportive family environments found in other women seeking testing and may require counseling or other mental health services to assist them with elevated levels of psychological distress.

One goal of this study was to identify behavioral evidence for the tend-and-befriend theory of stress (Taylor et al., 2000). Unfortunately, this study was unsuccessful

at establishing a clear connection of increased affiliative behaviors for women experiencing stress. The number of individuals in the support network was not related to psychological distress or satisfaction with social support. The size of the sample made it very difficult to detect an effect. The means, however were very similar, leading to the conclusion that social support satisfaction truly did not differ between the groups. It is also possible that the women who participated in this genetic testing program do not perceive the genetic testing to be a major stressor. Testing may actually serve to reduce stress by providing objective evidence of risk. A modification that would improve this analysis is having women rate the perceived level of stress they experience throughout the genetic testing process. It may be that changes in network size or satisfaction occur with testing.

As for the "tend" portion of this tend-and-befriend theory (Taylor et al., 2000), there was some evidence that these women engaged in nurturing, supportive family environments. The high levels of cohesion and expressiveness, along with low levels of conflict are indicative of a nurturing environment. Once again, examining family environments over time and comparing the results with perceived stress could strengthen this finding.

Limitations

Several limitations of this study need to be addressed, the most salient of which is the sample size. Researchers guard against Type I error, rejecting the null hypothesis when in fact it is true, but often tend to ignore Type II errors. A Type II error is not finding a difference when a difference actually exists, often due to low power. The more

power an analysis has, the better the chance of rejecting a false null hypothesis and finding a difference. There are primarily four factors that affect power. These are the probability of a Type I error (alpha), the true alternative hypothesis, the sample size and variance, and the particular test employed (Howell, 1992). The easiest variable to manipulate is sample size. For this study, increasing sample size would have increased power. Effect size (the degree of overlap between the sampling distributions) is also very important. A rule of thumb for research is a small effect size is .20, medium is.50, and large is .80. Thus, a much larger sample would be needed to find differences with small effects.

A second limitation is the homogeneity of the sample which made it difficult to identify comparison groups. The majority of participants were Caucasian, well-educated, married women. This prevented any comparisons based on ethnicity, education, marital status, and socioeconomic status. As genetic testing becomes more widely available, women of varying levels of socioeconomic status will be accessing these services. Identification of predictors of distress will enhance health care professionals' ability to provide genetic counseling and target high-risk individuals for early intervention.

A third limitation pertains to the social support questionnaire. The advantages of this measure (Sarason, Sarason, Shearin, & Pierce, 1987) are that it assesses both the number of individuals in a network as well as the satisfaction with the support provided. It also allows for the identification of category of support provider (i.e., mother, friend, therapist). The major limitation, however, was the inability to identify gender of all support providers. Gender of support provider was available for all first- and second-

degree relatives reported, but the gender of friends, cousins, and helping professionals could not be identified. As expected, there were more females than males in the support network for relatives. It is proposed, however, that the association would be stronger if female friends had been identified and included in the analysis.

A personal correspondence with the research assistant of Irwin Sarason and Barbara Sararson (authors of the SSQ-6) revealed another limitation of this social support measure (personal communication, March 22, 2001). It has been reported that the social satisfaction distribution is consistently skewed, with individuals reporting very high levels of satisfaction. This was evidenced in this sample of women as well. One hypothesized reason for this finding is the format of the questionnaire itself. Women are asked to list individuals whom they feel provide them with help and support. If a person did not provide support that was perceived as helpful, chances are that person was not listed. For instance, if I was not satisfied with the support my mother provided, I would not include her on a list of individuals who I turn to for acceptance and cheering up. Therefore, only those individuals that are providing social support that is deemed satisfactory are provided. This does not allow for much variance in reported social support satisfaction.

A fourth limitation was the inability to clearly assess tend-and-befriend behaviors. First, to truly assess that females are exhibiting affiliative behaviors as a female response to stress, a male comparison group is necessary. Obviously, that was not a possibility for this study. Future studies, however can examine both males and females with cancer and correlate affiliative behaviors with reported stress experiences (e.g., diagnosis, treatment,

recurrence) to determine whether females respond differently than males in regards to family environment and social support networks. Another suggested modification would be to examine support networks over time. This study utilized data from the second visit, with the assumption that this is a very stressful time for participants as they waited for genetic test results. Possibly looking at changes in network composition, size, and satisfaction across the five visits would reveal a relationship between social support and distress.

Finally, the data used in this study was self-reported by the participants. Self-reported data should be used with caution due to biases and possible inaccuracies. The women in this study reported on their perceptions of their family environments, which may differ significantly from the objective reality of these family relationships. It should be noted, whether it is objective reality or not, that these women perceive their interactions with their families to be a certain way. That perception is important because that is their reality of what they are experiencing.

Future Work

The results and limitations have implications for future research. First, studies should examine these issues, specifically family environment analyses, with a larger sample. With more statistical power, significant differences may be revealed regarding family cancer history, affiliative behaviors, family environments, and psychological distress. Identification of affiliative patterns that moderate or buffer stress would assist health care professionals in the identification and treatment of individuals who are at

high-risk for psychological distress while pursuing genetic testing and/or being diagnosed and treated for cancer.

Second, studies should examine the relationship of family resources and personal coping style. Family resources combined with personal resources have been found to predict stress resistance (Moos & Moos, 1986). It is possible that certain family dynamics paired with a personal style of dealing with problems will interact to decrease reported psychological distress. A comprehensive assessment of patient resources would allow for a better understanding of the individual as well as provide a guide for clinicians to recommend interventions.

Finally, this study did not examine the religious affiliation of the participants and its relation to family environment and social support networks. A large number of women in this sample described their family environments as having a strong moral-religious emphasis. Future research should include questions pertaining to religious affiliation as well as level of religiosity to begin to determine the role of organized religion and affiliative behaviors.

Genetic testing is a rapidly growing field, which brings a plethora of both advantages and disadvantages with it. One clear advantage is the knowledge of objective health risks, which allows for preventive care, such as mammography and surveillance behaviors. Disadvantages include issues regarding confidentiality and rights to privacy as well as possible increased distress, guilt of passing mutations to children, and fatalistic thinking. This is an important field for psychologists. This study provided the first exploratory findings on affiliative behaviors of community women seeking BRCA1 and

BRCA2 genetic testing. Continued systematic examination of individuals presenting for genetic testing will enhance our understanding of the risk notification process as well as enhance the development of appropriate and efficient interventions.

Table 1

Continuous Demographic and Medical/Family History Variables

Variable	Range	Mean	SD
Age	28.3 – 76.9	45.51	12.34
Education	2 - 6	3.80	1.02
# First Degree Relatives with Breast/ Ovarian Cancer	0 - 3	.86	.75
# First Degree Relatives with Breast Cancer	0 – 3	.86	.75
# First Degree Relatives with Ovarian Cancer	0 - 1	.02	.14
# First Degree Relatives with Other Cancers	0 - 3	.61	.72
# First Degree Relatives	0 - 4	1.49	.98
# Second Degree Relatives	0 - 7	2.29	1.79
# Total Relatives with Any Cancer	1 - 9	3.78	2.00

Table 2

Categorical Demographic and Medical/Family History Variables

Variable	Frequency	Percentage
Marital Status		
Single	7	13.7
Married	41	80.4
Divorced	1	2
Widowed	2	3.9
Race		
Caucasian	48	94.1
African American	1	2.0
Other	2	3.9
Ashkenazi Jewish Ethnicity		
Yes	8	15.7
No	43	84.3
Currently Employed		
Yes	37	72.5
No	14	27.5

Table 3

Family Type Categorization

Family Type	Frequency	Percent
Women with FDRs with BOC	26	72.2
Independence-Oriented	5	19.2
Achievement-Oriented	4	15.4
Structured Moral-Religious	14	53.8
Unstructured Moral-Religious	2	7.7
Support-Oriented	1	3.8
Women without FDRs with BOC	10	27.8
Independence-Oriented	3	30.0
Structured Moral-Religious	6	60.0
Support-Oriented	1	10.0
Women with Personal Cancer History	21	58.3
Independence-Oriented	7	33.3
Achievement-Oriented	1	4.8
Structured Moral-Religious	11	52.4
Support-Oriented	2	9.5
Women without Personal Cancer History	15	41.7
Independence-Oriented	1	22.2
Achievement-Oriented	3	11.1
Structured Moral-Religious	9	55.6
Unstructured Moral-Religious	2	5.6

Note. Family type categorization was made using criterion in the Family Environment Scale (Moos & Moos, 1986).

Table 4

Comparisons of FES Subscales for Women with and without Personal Cancer History

Subscale	Women with Cancer History M	SD	Women without Cancer History M	SD	t	p
Cohesion	7.50	(1.78)	7.58	(1.68)	-.16	.89
Expression	5.80	(1.73)	6.37	(1.71)	-1.13	.27
Conflict	2.17	(1.82)	1.94	(1.90)	.40	.69
Independence	6.87	(1.74)	6.89	(1.59)	-.06	.96
Achievement	5.20	(1.69)	5.58	(2.14)	-.69	.49
Intellectual-Cultural	6.13	(2.11)	6.26	(2.00)	-.21	.83
Active-Recreational	6.20	(2.06)	6.21	(1.93)	-.02	.99
Moral-Religious	5.63	(2.31)	6.52	(2.27)	-1.33	.19
Organization	6.30	(1.62)	6.89	(2.13)	-1.11	.27
Control	4.03	(1.73)	4.79	(2.04)	-1.39	.17

Table 5

Examination of HSCL Psychological Distress Scales of Women with and without FDRs with BOC

Distress	Women with FDRs with BOC M	SD	Women without FDRs with BOC M	SD	t	p
Somatization	1.40	(.30)	1.43	(.36)	.30	.76
Obsessive-Compulsive	1.60	(.54)	1.59	(.62)	-.03	.98
Interpersonal Sensitivity	1.51	(.46)	1.42	(.51)	-.64	.52
Depression	1.52	(.38)	1.41	(.55)	-.79	.43
Anxiety	1.30	(.42)	1.29	(.35)	-.13	.90
Total	1.47	(.32)	1.43	(.33)	-.44	.66

Table 6

Examination of HSCL Psychological Distress Scales of Women with and without Personal Cancer History

	Women with Cancer History		Women without Cancer History			
Distress	M	SD	M	SD	t	p
Somatization	1.45	(.32)	1.34	(.30)	1.28	.21
Obsessive-Compulsive	1.59	(.53)	1.60	(.60)	-.04	.97
Interpersonal Sensitivity	1.55	(.50)	1.39	(.40)	1.14	.26
Depression	1.47	(.40)	1.53	(.50)	-.48	.64
Anxiety	1.34	(.45)	1.24	(.32)	.87	.39
Total	1.48	(.34)	1.43	(.30)	.56	.58

Table 7

Social Support Network Descriptors

Support Provider	Range	M	SD
Number of Relatives	0 – 9	4.39	1.84
Number of Friends	0 – 9	2.65	2.00
Number of Females	0 – 5	2.20	1.31
Number of Males	0 - 3	1.37	1.06

Table 8

Correlations of Number and Gender of Support Providers and HSCL Psychological Distress Scales

	# of Providers	# of Females	# of Males
Somatization	-.12	-.14	-.04
Obsessive	.12	-.05	.02
Interpersonal	.01	.14	-.09
Depression	-.05	.02	-.14
Anxiety	-.03	.09	-.05
Total	-.02	.01	-.08

Note. None of the above correlations are significant at $p < .05$.

Table 9

Family Types for all Women

Family Type Classification	Frequency	Percentage
Personal Growth-Oriented	34	94.4
Independence	8	15.7
Achievement	4	7.8
Structured Moral-Religious	20	39.2
Unstructured Moral-Religious	2	3.4
Relationship-Oriented	2	5.6
Support	2	3.9

Note. Family type classifications were made using criterion in the Family Environment Scale (Moos & Moos, 1986).

Table 10

FES Subscale Mean Comparison for Ashkenazi Jewish Women in Study with Normal and Distressed Families

Subscale	Sample Mean	Z (Normal) Families	Z (Distressed) Families
Cohesion	5.63	-2.04*	.86
Expressiveness	6.00	1.00	2.26*
Conflict	3.75	.68	-.78
Independence	7.50	2.12*	3.66***
Achievement	5.25	-.39	-.07
Intellectual-Cultural	6.63	1.64	3.20**
Active-Recreational	5.00	-.53	2.02*
Moral-Religious	3.00	-2.54*	-2.20*
Organization	5.88	.72	1.22
Control	3.75	-.92	-1.65

* $p < .05$. ** $p < .01$.*** $p < .001$.

Table 11

FES Subscale Mean Comparison for all Women in Study with Normal and Distressed Families

Subscale	Mean	Z (Normal) Families	Z (Distressed) Families
Cohesion	7.53	4.84***	8.93***
Expressiveness	6.02	2.59**	5.68***
Conflict	2.08	-4.73***	-7.85***
Independence	6.88	1.59	5.50***
Achievement	5.35	-.52	.27
Intellectual-Cultural	6.18	2.20*	6.27***
Active-Recreational	6.20	3.15**	7.35***
Moral-Religious	5.98	4.50***	5.67***
Organization	6.53	4.31***	5.44***
Control	4.33	.04	-2.00*

* $p < .05$. ** $p < .01$. *** $p < .001$.

Table 12

Mean Psychological Distress for each Family Type

Distress	n	M	SD
Somatization			
Independence	8	1.57	.38
Achievement	4	1.58	.30
Structured Moral-Religious	20	1.37	.32
Unstructured Moral-Religious	2	1.17	.01
Support	2	1.67	.24
Obsessive-Compulsive			
Independence	8	1.52	.50
Achievement	4	1.94	1.01
Structured Moral-Religious	20	1.46	.42
Unstructured Moral-Religious	2	1.69	.09
Support	2	2.50	.71
Interpersonal Sensitivity			
Independence	8	1.46	.45
Achievement	4	1.46	.51
Structured Moral-Religious	20	1.41	.42
Unstructured Moral-Religious	2	1.36	.10
Support	2	1.50	.30
Depression			
Independence	8	1.52	.37
Achievement	4	1.73	.26
Structured Moral-Religious	20	1.30	.29
Unstructured Moral-Religious	2	1.54	.13
Support	2	1.50	.19
Anxiety			
Independence	8	1.38	.45
Achievement	4	1.50	.45
Structured Moral-Religious	20	1.20	.29
Unstructured Moral-Religious	2	1.08	.12
Support	2	1.33	.23
Total Distress			
Independence	8	1.50	.32
Achievement	4	1.65	.29
Structured Moral-Religious	20	1.35	.25
Unstructured Moral-Religious	2	1.36	.01
Support	2	1.73	.11

Appendix A

Demographic Form

BCREP# __ __ __ __ __ __ __ __ __ __ __ __ Date: _____ / _____ / _____

mm dd yy

Contact Information:

Last Name _____ First Name _____

Address _____

City _____ State _____ Zip _____

Home Phone (_____) _____ (AM / PM)

Work Phone (_____) _____ (AM / PM)

Demographics:

Date of Birth _____ / _____ / _____
mm dd yy

Marital Status:
1. Single (never married)
2. Married
3. Divorced
4. Separated
5. Widowed

Ethnicity:
1. Caucasian (Not Hispanic)
2. African American
3. Hispanic
4. Other _____

Ashkenazi Status:
1. Yes
2. No

Education:
1. Elementary
2. High Schoool
3. Some College
4. College Degree
5. Graduate Degree
6. Professional School

Breast Health:

Last CBE: _____/_____/_____
mm dd yy

Does Breast Self Exam: 1. Yes
2. No

(If Yes) Frequency: _____

Confident in BSE: 1. Yes
2. No

Hx of Breast Problems: 1. Yes
2. No

(If Yes)
Type of Breast Problem: 1. Cancer
2. Fibrocystic
3. Other_____

Previous Breast Biopsy: 1. Yes
2. No

(If Yes) No. of Biopsies: 1. One
2. Two
3. Three
4. Four
5. More than four

Past/Present Occupation: _____

Current Employment: 1. Full-time 2. Part-time 3. Unemployed 4. Homeworker 5. Retired

Cancer Information:

Personal Cancer Hx: 1. Yes 2. No (If Yes, list dx date and type, list earliest first by dx date)

Dx date: 1st: _____/_____/_____ 2nd:_____/_____/_____ 3rd:_____/_____/_____

Cancer: Type:_____ Type:_____ Type:_____

(Visit #1 and #2 done together at the same time: 1. Yes, 2. No).

First-degree Blood Relatives with Cancer:

A) First-degree Blood Relationship:
1. Parent - Mother
2. Parent - Father
3. Sibling - Sister
4. Sibling - Brother
5. Child - Daughter
6. Child - Son

Date of Birth: _____/_____/_____ Date of Dx: ___/___/___ Age at Dx: _____
Cancer Type: _____ Date of Death: ___/___/___ Ageat Death: _____

B) First-degree Blood Relationship:
1. Parent - Mother
2. Parent - Father
3. Sibling - Sister
4. Sibling - Brother
5. Child - Daughter
6. Child - Son

Date of Birth: _____/_____/_____ Date of Dx: ___/___/___ Age at Dx: _____
Cancer Type: _____ Date of Death: ___/___/___ Ageat Death: _____

C) First-degree Blood Relationship:
1. Parent - Mother
2. Parent - Father
3. Sibling - Sister
4. Sibling - Brother
5. Child - Daughter
6. Child - Son

Date of Birth: _____/_____/_____ Date of Dx: ___/___/___ Age at Dx: _____
Cancer Type: _____ Date of Death: ___/___/___ Ageat Death: _____

D) First-degree Blood Relationship:
1. Parent - Mother
2. Parent - Father
3. Sibling - Sister
4. Sibling - Brother
5. Child - Daughter
6. Child - Son

Date of Birth: _____/_____/_____ Date of Dx: ___/___/___ Age at Dx: _____
Cancer Type: _____ Date of Death: ___/___/___ Ageat Death: _____

E) First-degree Blood Relationship:
1. Parent - Mother
2. Parent - Father
3. Sibling - Sister
4. Sibling - Brother
5. Child - Daughter
6. Child - Son

Date of Birth: _____/_____/_____ Date of Dx: ___/___/___ Age at Dx: _____
Cancer Type: _____ Date of Death: ___/___/___ Ageat Death: _____

Second-degree Blood Relatives with Cancer:

A) Second-degree Blood Relationship: 1. Aunt
2. Uncle
3. Grandmother
4. Grandfather
5. Half-sister
6. Half-brother

Parental side: 1. Maternal
Maternal side: 2. Paternal

Date of Birth: _____/_____/_____ Date of Dx: ___/___/___ Age at Dx: _____
Cancer Type: _____ Date of Death: ___/___/___ Age at Death: _____

B) Second-degree Blood Relationship: 1. Aunt
2. Uncle
3. Grandmother
4. Grandfather
5. Half-sister
6. Half-brother

Parental side: 1. Maternal
Maternal side: 2. Paternal

Date of Birth: _____/_____/_____ Date of Dx: ___/___/___ Age at Dx: _____
Cancer Type: _____ Date of Death: ___/___/___ Age at Death: _____

C) Second-degree Blood Relationship: 1. Aunt
2. Uncle
3. Grandmother
4. Grandfather
5. Half-sister
6. Half-brother

Parental side: 1. Maternal
Maternal side: 2. Paternal

Date of Birth: _____/_____/_____ Date of Dx: ___/___/___ Age at Dx: _____
Cancer Type: _____ Date of Death: ___/___/___ Age at Death: _____

D) Second-degree Blood Relationship: 1. Aunt
2. Uncle
3. Grandmother
4. Grandfather
5. Half-sister
6. Half-brother

Parental side: 1. Maternal
Maternal side: 2. Paternal

Date of Birth: _____/_____/_____ Date of Dx: ___/___/___ Age at Dx: _____
Cancer Type: _____ Date of Death: ___/___/___ Age at Death: _____

E) Second-degree Blood Relationship: 1. Aunt
2. Uncle
3. Grandmother
4. Grandfather
5. Half-sister
6. Half-brother

Parental side: 1. Maternal
Maternal side: 2. Paternal

Date of Birth: _____/_____/_____ Date of Dx: ___/___/___ Age at Dx: _____
Cancer Type: _____ Date of Death: ___/___/___ Age at Death: _____

Second-degree Blood Relatives with Cancer: (continued)

F) Second-degree Blood Relationship: 1. Aunt
2. Uncle
3. Grandmother
4. Grandfather
5. Half-sister
6. Half-brother

Parental side: 1. Maternal
Maternal side: 2. Paternal

Date of Birth: _____/_____/_____ Date of Dx: ___/___/___ Age at Dx: _____
Cancer Type: _____ Date of Death: ___/___/___ Age at Death: _____

G) Second-degree Blood Relationship: 1. Aunt
2. Uncle
3. Grandmother
4. Grandfather
5. Half-sister
6. Half-brother

Parental side: 1. Maternal
Maternal side: 2. Paternal

Date of Birth: _____/_____/_____ Date of Dx: ___/___/___ Age at Dx: _____
Cancer Type: _____ Date of Death: ___/___/___ Age at Death: _____

H) Second-degree Blood Relationship: 1. Aunt
2. Uncle
3. Grandmother
4. Grandfather
5. Half-sister
6. Half-brother

Parental side: 1. Maternal
Maternal side: 2. Paternal

Date of Birth: _____/_____/_____ Date of Dx: ___/___/___ Age at Dx: _____
Cancer Type: _____ Date of Death: ___/___/___ Age at Death: _____

I) Second-degree Blood Relationship: 1. Aunt
2. Uncle
3. Grandmother
4. Grandfather
5. Half-sister
6. Half-brother

Parental side: 1. Maternal
Maternal side: 2. Paternal

Date of Birth: _____/_____/_____ Date of Dx: ___/___/___ Age at Dx: _____
Cancer Type: _____ Date of Death: ___/___/___ Age at Death: _____

J) Second-degree Blood Relationship: 1. Aunt
2. Uncle
3. Grandmother
4. Grandfather
5. Half-sister
6. Half-brother

Parental side: 1. Maternal
Maternal side: 2. Paternal

Date of Birth: _____/_____/_____ Date of Dx: ___/___/___ Age at Dx: _____
Cancer Type: _____ Date of Death: ___/___/___ Age at Death: _____

Other relevant Information (including third-degree relatives, etc.): 1. Yes 2. No (if Yes, continue notes on back)

Appendix B
Hopkins Symptom Checklist (HSCL)

Instructions: Below is list of problems and complaints that people sometimes have. Please read each one carefully. After you have done so, please rate how much that problem has bothered or distressed you DURING THE PAST WEEK INCLUDING TODAY. To make your ratings, use the scale shown below and circle your rating number for each item:

1 = Not at all **2** = A little bit **3** = Quite a bit **4** = Extremely

EXAMPLE: If you feel that "backaches" have been bothering you quite a bit during the past week, you would record your response as shown below:

Example. Backaches Example. 1 2 (3) 4

During the past week, including today, how much were you bothered by:		**1**	**2**	**3**	**4**
1. Headaches	1.	1	2	3	4
2. Nervousness or shakiness	2.	1	2	3	4
3.Being unable to get rid of bad thoughts or ideas	3.	1	2	3	4
4. Faintness or dizziness	4.	1	2	3	4
5. Loss of sexual interest or pleasure	5.	1	2	3	4
6. Feeling critical of others	6.	1	2	3	4
7. Bad dreams	7.	1	2	3	4
8. Difficulty in speaking when you are excited	8.	1	2	3	4
9. Trouble remembering things	9.	1	2	3	4
10. Worried about sloppiness or carelessness	10.	1	2	3	4
11. Feeling easily annoyed or irritated	11.	1	2	3	4
12. Pains in the heart or chest	12.	1	2	3	4
13. Itching	13.	1	2	3	4
14. Feeling low in energy or slowed down	14.	1	2	3	4
15. Thoughts of ending your life	15.	1	2	3	4
16. Sweating	16.	1	2	3	4
17. Trembling	17.	1	2	3	4
18. Feeling confused	18.	1	2	3	4
19. Poor appetite	19.	1	2	3	4
20. Crying easily	20.	1	2	3	4
21. Feeling shy or uneasy with the opposite sex	21.	1	2	3	4
22. A feeling of being trapped or caught	22.	1	2	3	4
23. Suddenly scared for no reason	23.	1	2	3	4
24. Temper outbursts	24.	1	2	3	4
25. Constipation	25.	1	2	3	4
26. Blaming yourself for things	26.	1	2	3	4

1 = Not at all **2** = A little bit **3** = Quite a bit **4** = Extremely

During the past week, including today, how much were you bothered by:		**1**	**2**	**3**	**4**
27. Pains in the lower part of your back	27.	1	2	3	4
28. Feeling blocked in getting things done	28.	1	2	3	4
29. Feeling lonely	29.	1	2	3	4
30. Feeling blue	30.	1	2	3	4
31. Worrying too much about things	31.	1	2	3	4
32. Feeling no interest in things	32.	1	2	3	4
33. Feeling fearful	33.	1	2	3	4
34. Your feelings being easily hurt	34.	1	2	3	4
35. Having to ask others what you should do	35.	1	2	3	4
36. Feeling others do not understand	36.	1	2	3	4
37. Feeling that people are unfriendly or dislike you	37.	1	2	3	4
38. Having to do things very slowly to insure correctness	38.	1	2	3	4
39. Heart pounding or racing	39.	1	2	3	4
40. Nausea or upset stomach	40.	1	2	3	4
41. Feeling inferior to others	41.	1	2	3	4
42. Soreness of the muscles	42.	1	2	3	4
43. Loose bowel movements	43.	1	2	3	4
44. Trouble falling asleep	44.	1	2	3	4
45. Having to check and double check what you do	45.	1	2	3	4
46. Difficulty making decisions	46.	1	2	3	4
47. Wanting to be alone	47.	1	2	3	4
48. Trouble getting your breath	48.	1	2	3	4
49. Hot or cold spells	49.	1	2	3	4
50. Having to avoid certain things, places or activities because they frighten you	50.	1	2	3	4
51. Your mind going blank	51.	1	2	3	4
52. Numbness or tingling in parts of your body	52.	1	2	3	4
53. A lump in your throat	53.	1	2	3	4
54. Feeling hopeless about the future	54.	1	2	3	4
55. Trouble concentrating	55.	1	2	3	4
56. Feeling weak in parts of your body	56.	1	2	3	4
57. Feeling tense or keyed up	57.	1	2	3	4
58. Heavy feelings in your arms or legs	58.	1	2	3	4

Appendix C
Social Support Questionnaire 6

INSTRUCTIONS: The following questions ask about people in your environment who provide you with help or support. Each question has two parts. For the first part, list all the people you know, excluding yourself, whom you can count on for help or support in the manner described. Give the person's initials, their relationship to you (see sample). Do not list more than one person next to each of the numbers beneath each question.

For the second part, circle how satisfied you are with the overall support you have.

If you have had no support for a question, check the words "No one," but still rate your level of satisfaction. Do not list more than nine persons per question.

Please answer all the questions as best you can. All your responses will be kept confidential.

EXAMPLE. Who do you know whom you can trust with information that could get you in trouble?

___ No one 1) T.N. (sister) 4). R.N. (daughter) 7)

2) B.P. (friend) 5) 8)

3) S.S. (friend) 6) 9)

B. How satisfied?

6 - very satisfied	5 - fairly satisfied	4 - a little satisfied	3 - a little dissatisfied	2 - fairly dissatisfied	1 - very dissatisfied

---

1.A. Whom can you really count on to be dependable when you need help?

___ No one 1) 4) 7)

2) 5) 8)

3) 6) 9)

B. How satisfied?

6 - very satisfied	5 - fairly satisfied	4 - a little satisfied	3 - a little dissatisfied	2 - fairly dissatisfied	1 - very dissatisfied

2. A. Whom can you really count on to be dependable when you need help?

___ No one 1) 4) 7)

2) 5) 8)

3) 6) 9)

B. How satisfied?

6 - very satisfied	5 - fairly satisfied	4 - a little satisfied	3 - a little dissatisfied	2 - fairly dissatisfied	1 - very dissatisfied

SSQ6 (continued)

3. A. Whom can you really count on to be dependable when you need help?

___ No one 1) 4) 7)

2) 5) 8)

3) 6) 9)

B. How satisfied?

6 - very satisfied	5 - fairly satisfied	4 - a little satisfied	3 - a little dissatisfied	2 - fairly dissatisfied	1 - very dissatisfied

4.A. Whom can you really count on to be dependable when you need help?

___ No one 1) 4) 7)

2) 5) 8)

3) 6) 9)

B. How satisfied?

6 - very satisfied	5 - fairly satisfied	4 - a little satisfied	3 - a little dissatisfied	2 - fairly dissatisfied	1 - very dissatisfied

5.A. Whom can you really count on to be dependable when you need help?

___ No one 1) 4) 7)

2) 5) 8)

3) 6) 9)

B. How satisfied?

6 - very satisfied	5 - fairly satisfied	4 - a little satisfied	3 - a little dissatisfied	2 - fairly dissatisfied	1 - very dissatisfied

6.A. Whom can you really count on to be dependable when you need help?

___ No one 1) 4) 7)

2) 5) 8)

3) 6) 9)

B. How satisfied?

6 - very satisfied	5 - fairly satisfied	4 - a little satisfied	3 - a little dissatisfied	2 - fairly dissatisfied	1 - very dissatisfied

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